

## **Information to guardians about the Swedish Pediatric Stroke Register (Barn-Riksstroke)**

The Swedish Pediatric Stroke Register, “Barn-Riksstroke”, is part of Riksstroke, a national quality register based in Västerbotten County Council (Region Västerbotten). The purpose of the register is to promote good care for all stroke patients, no matter where they live, their gender or age. As of 1998, all hospitals in Sweden submit information to the register and as of 2016, children are also included. The register is funded by the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SKR – Sveriges Kommuner och Regioner).

Stroke is a generic term for a blood clot or bleeding in the brain. Stroke is much more common among adults and the elderly, than among children but it is estimated that every year in Sweden, about one hundred children between the ages of 1 month and 18 years suffer a stroke. Knowledge about stroke among children is continually increasing and international studies have shown that adequate examination and treatment, both at the acute stage and during the follow-up period, are of significance for the child’s future wellbeing and neurological functions. The purpose of the register is to ensure that children who suffer a stroke are correctly examined, treated and followed up irrespective of where they live in Sweden or where they are when they become ill. The goal is that every child will be able to function as well as possible in different areas and have access to the support he/she needs.

### **How is registration done?**

The child’s doctor registers information about the examinations that were done, the results of the examinations, and the treatment given up to one year after the stroke. Questionnaires are sent to the child’s guardians 3 and 12 months after the stroke.

### **Which children can be included?**

All children who suffered a stroke between the ages of 1 month to 18 years are welcome to be part of the pediatric stroke register. Participation is voluntary and patients have the right to terminate their participation at any time without having to give any reason. For those who participate, all information about the child’s examinations, treatment and functional abilities will be registered in a national quality register, unless explicitly requested otherwise.

### **Why?**

We believe that by gathering information about child stroke patients from the whole of Sweden for analysis and evaluation, it will be easier to develop and improve the quality of the healthcare given. The information that is gathered will also contribute to new knowledge about how one can best address the problem of stroke among children and young people.

### **Support in legislation**

All parties processing personal data must have legal grounds to do so. Processing of personal data in quality registries is regulated by the General Data Protection Regulation (GDPR) and chapter seven of the Swedish Patient Data Act (PDL). It is permitted to register data in a quality registry as the data is of public interest to society and vital within the field of medical care. The staff processing personal data in a quality registry are subject to statutory professional secrecy.

### **The handling of data**

Data about the child are gathered from the patient's medical file and from the guardians. The information about the child in the quality register may only be used to develop and improve the quality of stroke care, to produce statistics and for research in healthcare and medical care services. After a confidentiality assessment, data may be passed on to a party who will use the information for one of these three purposes. If an item of information can be released from the register, this can be done electronically. When data from the register are to be used for research purposes, approval by an ethics review board (EPM – *Etikprövningsmyndigheten*) is required.

The County Council of Västerbotten has the overall legal responsibility for the personal data in *The Swedish Pediatric Stroke Register*. The overall responsibility is centrally referred to as the controller (CPUA). The care unit assumes a local legal responsibility for the collection of data. You can also contact a Data Protection Officer with questions about your child's personal data in the quality registry.

### **Confidentiality**

Data about the child are subject to the confidentiality rules of healthcare and medical care under the Public Access to Information and Secrecy Act. This means that data may only be released from the register if it is clear that neither the child nor a close relative will suffer damage or injury if the information is released. The database is also subject to the rules of the Swedish Data Protection Authority. This means it will not be possible to identify any individual child when the data is compiled in general reports. Patients have the right to refuse to have their data registered in the national quality register without there being any effect on the care they receive or their contacts with healthcare services. Patients also have the right to have their data removed from the register (see the attached documents). More information about the pediatric stroke register can be found in the attached documents and on the [www.barnriksstroke.se](http://www.barnriksstroke.se) website. More information about national quality registers is available at [www.kvalitetsregister.se](http://www.kvalitetsregister.se).

### **Security**

Data about a child in the register are protected against unauthorized use. There are special requirements regarding security measures, for example, that only those who need the data about the child are allowed access to it, checks must be made that no unauthorized person has had access to the data, the data about the child must be protected through encryption, and that the data can only be accessed through a secure log in procedure.

### **Removal of data**

Data about the child will be removed when it is no longer needed to develop and improve the quality of pediatric stroke care.

### The rights of the child and the guardians

- Participation in the register is voluntary and does not affect the care given to the child. If you do not want data about your child to be reported to the register, please contact:  
Registerkoordinator Barnriksstroke,  
NKS, Karolinska Universitetssjukhuset  
Eugeniavägen 23, C10:33  
17176 Stockholm
- You have the right to have data about the child removed from the register at any time.
- Once a year, free of charge, you have the right to have information of what is registered about your child. You have the right to get the information in electronic form. In such case, send a written and signed request to:  
Regionstyrelsen för region Västerbotten, Norrlands Universitetssjukhus, 901 85 Umeå.  
E-mail: [dataskyddsbud@regionvasterbotten.se](mailto:dataskyddsbud@regionvasterbotten.se)
- You have the right to get a log extract with information about which care facility and at what time someone has had access to data about the child.
- Under certain conditions, you have the right to request that the processing of data concerning your child be restricted. This applies during the period when other objections are being assessed. The restriction means that the quality registry may not do anything with the data concerning you aside from continuing to store it.
- You have the right to have incorrect data concerning your child rectified and to have incorrect data supplemented.
- You have the right to compensation if personal data is handled in breach of the General Data Protection Regulations (GDPR) or the Patient Data Act (*Patientdatalagen, PDL*).
- You are entitled to submit complaints to the Swedish Data Protection Authority, which is the supervisory authority in this area.

## **Information to young people about the Swedish Pediatric Stroke Register (Barn-Riksstroke)**

**Stroke means** a blood clot or bleeding in the brain which can cause neurological symptoms that vary in degree of severity. Stroke is much more common among adults than among children but every year in Sweden, about one hundred children and young people suffer a stroke. As of 2016, Sweden's hospitals are collaborating in building up a data register of children and young people who suffer a stroke. With the help of the register, we want to ensure that every child or young person who has a stroke is given the correct treatment and help.

### **How is registration done?**

Your doctor registers information about the examinations and treatment you have received during the first year after you had the stroke. After 3 and 12 months, a questionnaire will be sent to you and your guardian with questions about how you are feeling and what treatment or training you are having.

### **Who can be included?**

All children and young people between the ages of 1 month up to 18 years who have suffered a stroke are welcome to be part of the register. Participation is voluntary. You have the right to terminate your participation at any time without having to give a reason why.

### **Why?**

Because it is unusual for children or young people to have a stroke, we believe that the data register will help us to improve the care given to stroke patients. We also believe it will be easier to ensure that every patient is given the care and help needed so as to cope as well as possible with the situation.

### **Confidentiality**

The data register is subject to the confidentiality rules of healthcare and the rules of the Swedish Data Protection Authority (GDPR). This means it will not be possible to identify specific information about you when the data is compiled into general reports. You have the right to refuse to have your data registered in the national quality register without that affecting the care you receive or your contacts with the healthcare services in any way. If you want to know what data about you are stored in the register, if you want data removed, or if you want to know how the data about you has been used, you have the right to do so. Your guardian or your doctor has precise information about how this is done. There is more information about the register in the information sheet for guardians and on the [www.barnriksstroke.se](http://www.barnriksstroke.se) website.

### **Contact details:**

If you would like more information about the register, use [www.barnriksstroke.se](http://www.barnriksstroke.se) website or contact:

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